
Findings from the NHS East of England Consultation

Executive Summary

Prepared by the

January 2011

This summary report and the full report, plus easy read and audio versions of the full report are available from the NHS East of England web site: http://www.eoe.nhs.uk/learningdisability.
Introduction

This is a summary of findings from the formal consultation on Better Health and Wellbeing for People with a Learning Disability and Family Carers in the East of England 2011 – 2021. The full report contains significant additional detail, and includes extracts from responses to illustrate the themes that emerged. The report, plus easy read and audio versions, are available from the NHS East of England web site: http://www.eoe.nhs.uk/learningdisability

Consultation took place between October 2010 and January 2011. NHS East of England sought feedback by asking key stakeholders to both give their own views and to distribute the Vision to other organisations and groups and encourage a response. It is clear that Learning Disability Partnership Boards and health organisations across the region made significant efforts to do so. The Vision was sent to:

- Primary Care Trusts, and through them to NHS provider Trusts.
- Practice based commissioning groups (GPs who buy services), Local Medical, Dental, Optical and Pharmacy Committees, Mental Health Trusts and the Ambulance Service Trust.
- Learning Disability Partnership Boards, which include people with a learning disability, family carers, adult and children’s social care services, education, housing and others.

A ‘Bigger Health Day’ was held for people with a learning disability and family carers to give feedback in person. 161 people took part, including 51 self-advocates and 14 family carers. People were supported to leave comments at twelve staffed ‘Give Us Your Views’ areas, and could also attend workshops to talk about the pathway through GP services to screening and hospital treatment.

The Vision was also available to the general public. Leaflets were distributed and people could access the documents through regional and local NHS websites.

Consultation questions

The Vision document identified twelve ‘key features and enablers of good health and wellbeing’, and discussed each in relation to current services and developments in the East of England. A specific vision was outlined for each feature, with a key commitment for the coming 10 years plus a shorter-term goal.

Individuals, groups and organisations were encouraged to give their views about: the current issues and services, the vision statements, and the commitments. Three specific questions were also asked:

- What do you like about the Vision and why?
- Is there anything you do not like and why?
- Is there anything you would add to the Vision?

The responses and the analysis

84 written and telephone responses were received, including from the 11 Learning Disability Partnership Boards in the region, 2 Commissioning groups (1 a GP Commissioning Consortia), and 7 NHS Provider Trusts. More detail is shown in the Table below.
### Table

<table>
<thead>
<tr>
<th>Category</th>
<th>Individuals</th>
<th>Groups</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-advocates</td>
<td>20</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Family carers</td>
<td>11</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Professionals &amp; others</td>
<td>6</td>
<td>16</td>
<td>22</td>
</tr>
<tr>
<td>Mixed stakeholder groups</td>
<td></td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Members of public</td>
<td>6</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>43</strong></td>
<td><strong>41</strong></td>
<td><strong>84</strong></td>
</tr>
</tbody>
</table>

358 individual comments were collected at the Bigger Health Day from self-advocates, family carers and professionals. The workshops also generated material which was treated as a group response and included in the analysis.

In total 431 responses were analysed. A weighting system was used to distinguish group responses from single person, and mixed stakeholder responses from single stakeholder. This indicated the strength of the response and helped to identify the key themes. Responses from mixed stakeholder groups were given the highest weighting.

### The Findings

This summary outlines the main findings, and simply cannot do proper justice to the detailed, considered comments people submitted. The full report goes into more depth.

#### Overall

The Vision has been well-received and is appreciated. Respondents welcome the fact that a Vision for the east of England has been produced, even if they don’t necessarily agree with all aspects of it. Learning Disability Partnership Boards were happy to see that their local work in response to Healthcare for All and Valuing People Now is reinforced by the Vision.

#### Things that are strongly supported

**the Vision to achieve equal access to, and better support from mainstream healthcare services**

Support was expressed across stakeholder groups. The focus on people’s right to be treated equitably, and use of the equalities legislative framework and Single Equality Assessments was specifically and positively welcomed. There is widespread support for action to achieve reasonable adjustments, and widespread consensus that it is needed. Respondents welcomed, in particular, the commitment to having hospital liaison nurses and health facilitators, ‘flagging’ of people with learning disabilities, improved access to health checks and screening, and Health Action Plans.

**the Vision for workforce development and training**

Support was evident across the board for improved training of staff working in healthcare settings, and for the involvement of people with learning disabilities.
and family carers in delivery. The need to focus on communication training was especially emphasised. Training is clearly seen as central to the Vision, to the achievement of reasonable adjustments and the delivery of quality healthcare.

the commitment to developing partnerships
There was wide and strong support for the Vision for partnerships with people with learning disabilities and family carers, and for partnerships with other services. People welcome the fact that the targets for involvement will be monitored, but called for the Vision to also focus on provision of adequate support so that people can undertake partnership roles effectively. The inclusion of partnerships to improve employment opportunities and support for people was especially welcomed as a positive step towards health and wellbeing.

the Vision for improved information and support for carers
Responses reinforced the Vision of improving carers’ assessments and support at all stages in the life journey of a learning disabled person. The commitment to meeting the healthcare needs of carers themselves was welcomed, but respondents want greater clarity about the support that the NHS will actually provide, and acknowledgement that people with learning disabilities can be carers in their own right.

the Vision for more joined-up, integrated working so that people experience seamless support
Action to achieve more joined-up working received positive support from across respondents. It was stressed that there is a long way to go from the current starting point, with integrated working “sadly lacking at present”. Respondents called for the Vision to give even greater emphasis to action that achieves integrated support plans and pathways, and multidisciplinary team work.

The biggest concerns about the Vision

there are significant concerns about “making it happen”
The concerns focus on -

• resources to support implementation;
• what needs to happen to achieve the vision – the ‘how’;
• ensuring that action happens – issues of leadership and accountability;
• monitoring implementation and outcomes; and
• sustainability of initiatives and improvements.

Professionals, in particular, are concerned about how the ambitions in the Vision will be resourced given “current financial stringencies”. Stakeholders are already experiencing issues around staff capacity to deliver the health and social care agenda for people with learning disabilities, and are conscious that plans for further savings are being made. There is also particular concern about how the training and workforce development agenda in the Vision will be funded. More guidance on resourcing the Vision is wanted.
There are concerns that, whilst the Vision sets a clear direction of travel, it does not say enough about how to get there. People want to see more about how the Vision will be taken forward to implementation, and how progress and outcomes will be monitored.

Recognising that NHS East of England will be disappearing in April 2012, and given forthcoming changes to health commissioning, there is significant desire for a clear statement about who will lead and sustain the Vision into the future. Questions have been raised about how the Vision, initiated by a regional body, fits with local decision-making, commissioning and leadership - and how it fits into local plans. People want to know how healthcare services will be held accountable and want to see more in the Vision, generally, on issues related to organisational and professional accountability for performance.

There is demand for the Vision to be clearer on all of these points.

**The learning disability community wants the outcomes to be achieved sooner**
People with learning disabilities, family carers and Partnership Boards want agencies to ‘get on with it’ and achieve the improvements needed as soon as possible. Many raised concerns about the overall timeframe for achieving the Vision, wanting all the commitments to be achieved sooner than 10 years or for additional short-term commitments and milestones to be specified.

**People want more emphasis on the role of schools and education providers**
The important role of schools and other education providers in helping to achieve the Vision was raised repeatedly. In particular, through health promotion, provision of sex and relationship education, and good transition planning in schools, and improvements to qualifying training for health professionals in colleges and Universities. There is a desire that the Vision gives more emphasis to developing partnerships with schools and professional training courses.

**There’s a need for work to improve support ‘in the community’**
Respondents raised a range of issues about the availability and quality of community support and how it impacts on people’s health and wellbeing. There is a call for these issues and service gaps to be more directly addressed through the Vision. They include, amongst others, access to specialist support ‘out of hours’, the need for faster support in a crisis; access to skilled community support for behavioural analysis and management; issues for people living in rural communities. The contribution that the wider community can make is also felt to need strengthening in the Vision, with strategies to engage local communities more.
the focus on prevention of environmental causes of learning disability is too narrow

Responses, whilst small in number, have strength of feeling - largely focused around the negative impact that focusing on Foetal Alcohol Syndrome could have on both mothers and people with learning disabilities. There is a call for the Vision to:

- include prevention of other causes of learning disability (such as genetic causes and inter-related marriage) to balance the focus on Foetal Alcohol Syndrome.
- focus more on improving pre-birth testing, counselling and maternity services
- emphasise the inherent value of people with learning disabilities

there's not enough attention to the supports needed for effective personalised health planning, choice and control

Responses suggest that personalised health planning (Health Action Planning) is not yet fully embedded across the region, and that a focus on improving quality as well as coverage should be considered. People raised the issue of balancing choice and control with a person's need for treatment and care, and called for the Vision to more directly address the need for increased availability of advocacy support, particularly for people who have difficulties communicating their wishes and views.

people want the role, contribution and skills of community learning disability teams to be clarified

There was both implied and explicit support for the Vision and targets for specialist learning disability services, but also a call for action to clarify the role of community learning disability teams and the health component within them. Respondents want the Vision to support the development of teams with appropriate knowledge and skills to help maintain people who present significant challenges in their local community.

there needs to be more focus on operational systems for sharing information

Respondents want the Vision to include action designed to improve the electronic systems for sharing information about individuals across health and social care, primary and secondary services.

greater attention needs to be paid to the diversity of the region's population

Whilst few comments were received about issues for people with learning disabilities from Black and Minority Ethnic communities, those that were raise important issues for the Vision. There is a call for more information about the changing ethnic profile within the Eastern region, consideration of specific action to improve outcomes for different groups, provision of cultural competence training and language support, single sex environments and same sex support,
and Equality Delivery Schemes (EDS)\textsuperscript{1} to be included as a mechanism for addressing local needs.

**Feedback on the consultation documents and process**

Many respondents had been involved in developing the Vision and had commented on an early draft. There were very positive comments about the process. There was particular praise for the efforts made to consult with self-advocates and family carers, and the easy read version of the Vision was welcomed. Some self-advocates, though, found it too hard to understand and suggestions for improvements were suggested. These recommend using inclusive communication approaches, other media formats (such as DVDs) and descriptions and examples that make the content appear more directly relevant.

\textsuperscript{1} Equality Diversity Schemes are plans made by organisations to ensure that they address the needs of all the local population.